2006 Legislative Report from the Vermont Department of Health

Implementation of a Vermont Advance Directive Registry

January 2006

VERMONT
DEPARTMENT OF HEALTH

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Implementation of a Vermont Advance Directive Registry
Report to the Legislature
In Accordance with Act 55
January 2006

In September 2005, the General Assembly enacted and the Governor signed into law H.115, which became designated Act 55: *An Act Relating to Advance Directives for Health Care.* Within 180 days of the effective date of Act 55, Section 1 of Act 55 requires the following of the Commissioner of Health:

(1) In consultation with all appropriate agencies and organizations, shall adopt rules to effectuate the intent of the law. The rules shall provide:

- At least one optional form of an advance directive with an accompanying form providing an explanation of choices and responsibilities,
- The form and content of clinician orders for life sustaining treatment, the use of experimental treatments, a model DNR order, DNR identification, revocation of a DNR identification, and consistent statewide emergency medical standards for DNR orders and advance directives for patients and principals in all settings.
- A description of when health care providers, health care facilities, and residential care facilities may access an advance directive in the registry.
- The process for securely submitting, revoking, amending, replacing, and accessing the information contained in the advance directive registry, and provisions for incorporating into the registry notifications of amendment, suspension, or revocation.

(2) Shall develop and maintain a registry to which a principal may submit his or her advance directive, including a terminal care document and a durable power of attorney.

(3) Shall provide to any individual who submits an advance directive to the registry a sticker that can be placed on a driver's license or identification card indicating that the holder has an advance directive in the registry.

(4) Shall provide on the department's public website information on advance directives and the registry to appropriate state offices.

Additionally, the commissioner of motor vehicles shall provide motor vehicle licenses and identity cards, as soon as existing licenses or cards have been depleted, which allow the license holder or card holder to

indicate that he or she has an advance directive and whether it is in the registry.

Report to the Legislature on Act 55

In accordance with Section 10, of Act 55, the commissioner of health is required to submit a report on or before January 15, 2006, to the chairs of the following committees: the house and senate committees on judiciary, the house committee on human services, and the senate committee on health and welfare. The report shall describe the status and utilization of the registry established by this act and educational efforts undertaken to inform Vermonters about the registry and advance directives. In addition, the commissioner shall make available annually information describing the utilization and status of the registry in an appropriate format to the public. The report submitted shall:

- Assess the advisability and feasibility of including do-not-resuscitate (DNR) orders in the registry, and recommend how to include them if doing so would be advisable and feasible;
- Recommend how to link organ donation designations on motor vehicle operator's licenses with the registry established by this act; and
- Recommend a method to communicate to citizens of this state, in conjunction with the renewal of motor vehicle operator's licenses, the advisability of having and periodically updating an advance directive, and of organ donation designations.

1 Status of Rulemaking

1.1 Rulemaking for optional advance directive forms, clinician orders for life sustaining treatment, experimental treatments, DNR identification, revocation of DNR identification, and consistent statewide emergency medical standards for DNR orders and advance directives for patients and principals in all settings.

The Vermont Department of Health is preparing a rulemaking proceeding for the end of January 2006, with completion by the April. Throughout the drafting of administrative rules the Vermont Department of Health has encouraged input from interested entities in order to facilitate a responsive rulemaking process. We expect the rules to be considered by ICAR at their January meeting.

The rulemaking is contingent on the final recommendations of a statewide advisory workgroup. Currently, we are in the process of drafting rules to address each of the required provisions and are consulting with other state and national entities on best practice models. The workgroup, which included a variety of stakeholders, worked diligently through the fall to develop an optional advance

directive form (see Section 2.2). The workgroup has revised the Vermont Ethics Network advance directives form so that it is consistent with Act 55. The Department of Health is also working with the Vermont Medical Society (VMS) to develop appropriate forms for a model clinician order and model do-not-resuscitate (DNR) orders and expects to receive comments from VMS by end of January...

1.2 Rulemaking on the process for securely submitting, revoking, amending, replacing and accessing the information contained in the registry.

The rules for these requirements have been defined and drafted according to the processes used by the vendor we planned to hire to implement the web-based registry (see section 2.1). As a new vendor is selected the processes for submitting, revoking, and amending advance directives, and the corresponding rules, may need to be revised.

2 Status of the Registry Development and Utilization

2.1 Development of the web-based Registry

To implement a web-based advance directive registry, the Vermont Department of Health planned to contract with an existing registry to develop and host a registry for Vermont. This approach would give Vermont a working registry faster and at lower cost than developing one from scratch. We posted a Request for Proposals on August 4 and received four proposals. We selected the proposal of Life's End Institute for their Choices Bank registry. Choices Bank is a web-based registry that has been operating successfully in Montana for nearly five years.

Unfortunately, after we selected Choices Bank for our contract, Life's End Institute transferred ownership of Choices Bank to St. Patrick Hospital and Health Sciences Center (Missoula, MT). The new owners are not interested in developing and hosting a Vermont advance directive registry as outlined in the original Life's End Institute proposal.

Therefore, we are reconsidering the other proposals we received in response to our RFP, and we are soliciting new proposals. We estimate a "go-live" date for the registry within approximately five months after signing a contract with a qualified vendor.

2.2 Development of a standard advance directives form

The advance directives form developed by the Vermont Ethics Network (VEN) has been widely distributed and well-received for many years. This form can serve as the "optional" form required by Act 55, but needed to be revised and adapted to meet the requirements of the law and the interests of stakeholders. John Campbell, Director of Vermont Ethics Network, and Wendy Morgan, Chief of the Attorney General's Public Protection Division, formed a workgroup to revise the VEN form. Meetings began on October 7, 2005 and met biweekly thereafter. The workgroup include representatives of Vermont Legal Aid, Vermont Protection and Advocacy, Vermont Medical Society. In addition comments on a draft version of the revised advance directives form were solicited and received from additional entities including the Vermont Hospital and Ethics Committee, Department of Aging and Independent Living (DAIL), Representative Anne Donahue and DAIL's Advisory Committee.

A draft version of the revised advance directives form was distributed 12/1/05 for comment to stakeholders from various organizations including the Attorney General Office, Vermont Hospital and Ethics Committee, Department of Aging and Independent Living (DAIL), Vermont Legal Aide, the Vermont Medical Society, and DAIL's Advisory Committee.

2.3 Registry Utilization

Standard utilization reports will be a part of the Registry design. Future reports to the legislature and to the public will include utilization statistics such as numbers and types of advance directives filed with the Registry sorted by demographic fields (e.g., age and residence of the registrant).

2.4 Registry Funding

In FY 2006 no general funds were allocated for the Advance Directive Registry. One of the Vermont Department of Health's partners in developing the registry, The Vermont Ethics Network, submitted a grant application to the Vermont Community Foundation for $25,000 to support the implementation, operation, and promotion of the registry, however this grant was not funded. The Governor's Health Initiative for fiscal year 2007 includes $50,000 new general fund dollars for Advance Directives, 21% of which is eligible to be included as an MCO investment item through Global Commitment.

2.5 Provider briefings on Act 55

In September and October of 2005, the Vermont Medical Society collaborated with stakeholders including the Department of Health to host interactive television educational sessions for healthcare providers regarding the new advance directive laws (see posting at http://www.vtmd.org/).

2.6 Public Education and Promotion Plan

The department is continuing to work with Vermont Medical Society, Department of Motor Vehicles, and Vermont Ethics Network to develop a comprehensive public education plan. The plan will promote understanding of the importance of having advance directives and the value of submitting advance directives to the registry to ensure timely and appropriate access. One component of the plan will capitalize on "teachable moments". For example, since people may express their willingness to make anatomical gifts on their motor vehicle licenses, renewal of a license may also present an opportune occasion for considering advance directives. Other components of the plan will include:

- Information about advance directives, organ donations, the registry, and a link to the registry on the Department of Health's website. Stakeholder organizations will be encouraged to link to the registry website as well.

- Point of service displays, brochures, posters, etc. in hospitals, physicians' offices, and places where people may complete or drop off advance directive forms for deposit into the registry (e.g., Department of Motor Vehicle offices, Department of Health district offices, area agencies on aging, etc.).

- Community meetings and conferences

- Optional forms of advance directives being available (e.g., for people with certain disabilities or limited English proficiency) to ensure that all citizens are afforded opportunities to have advance directives.

- Identifying with providers and insurers, additional opportunities within healthcare settings to facilitate discussing and enacting advance directives.

3 Advisability and feasibility of including DNR orders in the registry

Through discussions with stakeholders and analysis by the department's legal staff, we are continuing to assess the advisability and feasibility of including "do not resuscitate" (DNR) orders in the advance directive registry. The process for storing a DNR in the registry as a form of advance directive is technically simple. Our analysis to date, however suggests that there are important differences between DNR orders and advance directives, and that the principal benefits offered by a registry are not well suited for DNR orders. An advance directive is a legal document expressing an individual's preferences for care. A DNR is a medical document that may be subject to HIPAA (the Health Insurance Portability and Accountability Act of 1996) protections of security and confidentiality. Co-mingling them in the same registry complicates access controls. Registries are excellent tools for storing and making relatively static generalizable documents accessible across time and place. DNR orders are not static and may be very specific to a time and place (e.g., a particular hospitalization). They may expire, or may need to be reaffirmed after a period of time or for different episodes, or may be revoked.

Other issues have been raised as well. The process for depositing an advance directive into the registry could take several days, which may be too long to be useful for a DNR. Similarly, if a DNR on file in the registry were later suspended or revoked, the delay in recording the suspension in the registry would add more confusion to an already stressful situation. It is easy to imagine situations in which it would be preferable to have only original DNR orders on paper or physically attached to the patient with a bracelet, rather than having another copy filed electronically in the registry. The department is continuing to consider these issues carefully and therefore recommends not including DNR orders in the registry at this time.

4 Linking organ donation designations on motor vehicle operator's licenses with the registry.

Currently, individuals who wish to donate their tissues or organs upon death may check the appropriate boxes and sign the back of their Vermont motor vehicle license or identity card; or they may complete the organ donation advance directive form. Ideally, people who check the organ donor boxes on their motor vehicle license would also complete an advance directive and then file the advance directive with the registry. But these are separate actions, and the most direct way to link them is to integrate them: require that organ donations be done by advance directive and not by checking a box on the license/ID card. This could however have the unfortunate effect of reducing the number of people who donate organs, not because they don't want to but because they don't bother to complete the advance directive.

Short of integrating organ donation with advance directives, there are three other strategies to link the two. First, find ways to encourage everyone who designates organ donation on their license to also take the necessary steps to complete an advance directive, and to file it with the registry. For example:

- When applying for or renewing a license at the Department of Motor Vehicles, information will be provided encouraging licensees who have checked the organ donor checkbox to follow-through by completing and registering an advance directive.

- To simplify the process of completing the organ donor advance directive, Department of Motor Vehicle clerks will be trained to review advance directives forms to ensure completeness, and to witness signatures when requested by the applicant.

Second, capture the "wish" to make an anatomical gift using a simpler and more streamlined process than the advance directive process. For example, the individual could complete a card that contains the same information from the back of the driver's license, sign it, and send it to the Registry where it would be stored as a separate document. In this way, individuals who wish to donate their organs but who do not complete an organ donation advance directive would still have their wishes recorded in the Registry, and not merely checked on the back of their driver's licenses. This option recognizes that, even though the wish to donate organs may lack the authority of an advance directive, it nevertheless serves an important practical function in helping families make difficult decisions in the absence of an advance directive, and could be made more accessible with the Registry.

Third, capture and electronically store the "wish" to donate from the motor vehicle license and export that information to the Registry.

The first two options could be incorporated into the design of the Registry. The third is more complicated and would require changes to the Motor Vehicle data system.

ADVANCE DIRECTIVE FOR HEALTH CARE RULES
DRAFT OUTLINE
January 2006

I Purpose

These rules are adopted to effectuate the intent of Chapter 231 of Title 18, Vermont Statutes Annotated (VSA), Advance Directive for Health Care and Disposition of Remains.

The State of Vermont recognizes the fundamental right of an adult to determine the extent of health care the individual will receive, including treatment provided during periods of incapacity and at the end of life. 18 VSA Chapter 231 enables adults to retain control over their own health care through the use of advance directives, including appointment of an agent and directions regarding health care and disposition of remains. During periods of incapacity, the decisions by the agent shall be based on the express instructions, wishes, or beliefs of the individual, to the extent those can be determined.

II Definitions

The definitions of terms contained in these rules are the same as those contained in 18 VSA Chapter 231 at 18 VSA § 9701. If any of such legislative definitions are amended, the amended definitions shall be the definitions of the terms contained in these rules.

III Advance Directive Forms

- Optional form of an advance directive with an accompanying form providing an explanation of choices and responsibilities
- Clinician orders for life sustaining treatment (form and content)
- Use of experimental treatments
- Model DNR order which meets requirement of 18 VSA § 9708(a)
- DNR Identification
- Revocation of a DNR identification
- Consistent statewide emergency medical standards for DNR orders and advance directives for patients and principals in all settings

IV Advance Directives Registry

- What the Registry is
- When health care providers, health care facilities, and residential care facilities may access an Advance Directive in the Registry
- Prohibitions to access
- Statistical or analytical use of information (Individual's identifying information remains confidential)

- Process for securely submitting, revoking, amending, replacing, and accessing information contained in the Registry
- Incorporation into the Registry of notifications of amendment, suspension, or revocation under 18 VSA § 9704(c) and revocations of appointment under 18 VSA § 9704(d).

IV Advance Directive Registry

1. The Registry

The Advance Directive Registry is a secure, web-based database created by the Department of Health to which individuals may submit an advance directive or information regarding the location of an advance directive.

2. Access to Registry

The Advance Directive Registry is accessible to principals and agents and, as needed, to individuals appointed to arrange for the disposition of remains, organ procurement organizations, tissue and eye banks, health care providers, health care facilities, residential care facilities, funeral directors, crematory operators, cemetery officials, and the employees thereof.

3. Prohibitions to Access

In no event shall information in the Advance Directives Registry be accessed or used for any purpose unrelated to decision-making for health care or disposition of remains, except that the information may be used for statistical or analytical purposes as long as the individual's identifying information remains confidential.

4. Process

The following process shall be followed for securely submitting, revoking, amending, replacing, and accessing information in the Advance Directives Registry:

5. Amendment, Suspension, Revocation

Notification of amendment, suspension, or revocation under 18 VSA § 9704(c) and revocations of appointment under 18 VSA § 9704(d) shall be incorporated into the Advance Directive Registry.

ADVANCE DIRECTIVE FOR HEALTH CARE
Explanation and Instructions
(Final Working Draft 12-29-05)

An **Advance Directive** is a document you prepare to choose someone as your health care agent or to guide others to make health decisions for you, either about your health care or to take care of your body after you die. Having an Advance Directive helps when you no longer can or no longer wish to make your own decisions. As you begin your Advance Directive, here are some important things to know:

- You have the right to consent to or refuse any medical treatment.
- You have the right to appoint an ***agent*** to make decisions for you.
- You may use this advance directive to share your wishes ***in advance.***
- You may fill out all Parts of this Advance Directive form or just portions of it. For example, you can just appoint an agent in Part 1 and then sign Part 9. If you choose not to appoint an agent, you can skip part 1 and just give instructions in other Parts that you wish to fill out. However, if you fill out any Part of this document, you must also fill out Part 9, as it provides signatures and witnesses to validate the Advance Directive.

- You may use any Advance Directive form or format as long as it is properly signed and witnessed.
- You can revoke or suspend your Advance Directive at any time unless you expressly waive your right to do so.

Everyone needs an Advance Directive – not just those anticipating the end of their lives. Any of us could have an accident or suffer from an unexpected medical condition. Some of us live with a mental or physical illness that leaves us without capacity at times. Without an Advance Directive, those making decisions for you will not know what your wishes are. Worse still, your family and friends could fight over the care you should get. Help them help you -- do an Advance Directive.

This Advance Directive has 9 Parts. Fill out as few or as many Parts as you like today; if you want you can fill out other Parts another day. This is *your* document: change it as you like so that it states your wishes in your own words. You may cross out what you don't like and add what you want.

Updating your Advance Directive

It is very important to ensure the information in your Advance Directive is always current. Review it once a year or when events in your life change. People might consider the "5 D's" as times when their Advance Directive might need to be changed or updated: They are: decade birthday, diagnosis, deterioration, divorce or death of somebody close to you or in the news. All of these events may affect your values and thinking about future health care decisions for yourself.

You should also update addresses and contact information for your agent and alternate agent and other people such as potential medical guardians whom you may have identified in your Advance Directive.

REVOKING or Suspending your Advance Directive:

You may revoke your Advance Directive by completing a new Advance Directive or completing replacement Parts of this Advance Directive. Then the old Advance Directive or Part is no longer in effect and the new one replaces it. If the new one and the old one cover different subjects, then both will be in effect.

Suspending an Advance Directive is when you want a provision to not be in effect for a period of time. For example, you may have said you wanted a DNR order and the order may have been given to you. Then you need to go in for surgery and want the understanding that you will be revived during surgery if your heart stopped.

You may revoke or suspend all or part of your Advance Directive by doing any of the following things:

1. Signing a statement suspending or revoking the designation of your agent;
2. Personally informing your doctor and having him or her note that on your record;
3. By burning, tearing, or obliterating the Advance Directive either personally or at your direction when you are present; or
4. For any provision (other than designation of your agent), when you state orally or in writing, or by any other act of yours that indicates your intent to suspend or revoke any Part or statement contained in your Advance Directive.

Instructions for Part 1 - Appointment of My Health Care Agent

Appointing an agent to make decisions for you may be the single most important part of your Advance Directive. Your agent must be at least 18 years old and should be someone you know and trust. The person you choose should be someone who can make decisions for you, based upon your wishes and values. You *cannot* appoint your doctor or other health care clinician to be your agent. If you are in a nursing home or residential care facility, staff or owners cannot be your agents unless they are related to you. You can appoint an *alternate agent* to make decisions for you if your original agent is unavailable, unable, or unwilling to act for you. You can also appoint co-agents if you wish. (If you appoint co-agents, use the second page of this Part 1 form.)

The authority of your agent to make decisions for you can begin:

- when you no longer have the ***capacity*** to make decisions for yourself, such as when you are unconscious or cannot communicate, or
- ***immediately*** upon signing the advance directive *if you so specify, or*
- when a ***condition*** you specify is met, such as a diagnosis of a debilitating disease such as Alzheimer's Disease or serious mental illness, or
- when an ***event*** occurs that you want to mark the start of your agent's authority, such as when you move to a nursing home or other institution.

The authority of your agent will *end* when you regain capacity to make your own decisions or you may specify when you want your Advance Directive to be no longer in effect.

Once your Advance Directive goes into effect, your agent will have access to all your medical records and to persons providing your care. *Unless you state otherwise* in written instructions, your agent will have the same authority to make all decisions about your health care as you have.

Your agent will be obligated to follow your instructions when making decisions on your behalf to the extent that they apply. If you choose not to leave explicit written directions in other Parts of your Advance Directive, the persons making health care decisions for you will be guided by knowledge of your values and what is in your best interest at the time treatment is needed.

ADVANCE DIRECTIVE
(working DRAFT– 12-29-05)

My Name _____ **Date of Birth** _____**Date signed**_____

Address _____ **City**_____ **Zip**_____

Phone _____ Email: _____

Part 1 - My Health Care Agent

1. **I want my agent to make decisions for me:** (choose one statement below)
_____ when I am no longer able to make health care decisions for myself, or

_____ immediately, allowing my agent to make decisions for me right now, or

_____ when the following condition or event occurs (to be determined as follows):_____

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2. **I appoint** _____ as my health care **Agent** to make any and all health care decisions for me, *except to the extent that I state otherwise in this Advance Directive.* (You may cross out the italicized phrase if authority is unrestricted.)

Address _____Relationship (optional)_____
_____
Tel. (daytime) _____ cellphone _____
(evening)_____ email:_____

3. If this health care agent is unavailable, unable or unwilling to do this for me, **I appoint** _____to be my **Alternate Agent**.
Address: _____ Relationship (optional) _____
Tel. (daytime) _____ cellphone _____
(evening) _____ email: _____

*And if my Alternate Agent is unavailable, unable or unwilling to do this, **I appoint** as* **My Next Alternate Agent:** Name _____
Address: _____ Relationship (optional) _____
Tel. (daytime) _____ cellphone _____
(evening) _____ email: _____

4. _____ I want to appoint two or more people to be **co-agents** and have listed them on page two of this Part.

Appointment of "co-agents"

You can appoint co-agents – people you ask to make decisions for you, acting together, based upon a discussion of your circumstance and agreement on a course of action or treatment.

Not all of the people you ask to be co-agents may be readily available to speak for you or to make decisions that have to be made immediately, particularly in an emergency. For this reason, it is a good idea to give additional directions about how decisions could be made by those present.

1. Co-agents I appoint are:

Name _____ **Relationship (optional)**_____
Address _____
Phone (specify work, home or cell)_____
_____

Name _____ **Relationship (optional** _____
Address _____
Phone (specify work, home or cell) _____
_____

Name _____ **Relationship (optional)** _____
Address _____
Phone (specify work, home or cell) _____
_____

(repeat below for additional co-agents)

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2. I prefer that decisions made by the co-agents named above be made in the following way (you may choose one or prioritize 1,2,3):
   _____ by agreement of all co-agents
   _____ by a majority of those present, or
   _____ by the first person available, if it is an emergency.

3. Other Instructions for co-agents, as applicable:

Instructions for Part 2 – Others who may be involved in my care.

Part 2 is where you can list your current doctor or clinician and his or her address and phone number. This will help by identifying someone who knows your medical history.

You can also state who else should or should NOT be consulted about your care.

You can state who is to be given information about your medical condition. This list might include your children, even if they are minors, or your close friends. Hospitals are required to withhold information about your condition from people unless you or your agent gives permission that this can be shared

You can state who shall not be able to challenge decisions about your care in court actions. Normally any "interested individual" can bring an action in Probate Court regarding decisions made on your behalf. "Interested individuals" are your spouse, adult child, parent, adult sibling, adult grandchild, reciprocal beneficiary, clergy person or any adult who has exhibited special care and concern for you and who is personally familiar with your values. If there is someone in that list that you do *not* want to be able to bring an action to protect you, you may record the name of that person in Part 2.

Sometimes a court appoints a medical guardian for a person, and that person controls specific treatment decisions. You can state a preferred person that you would like the court to consider, if a medical guardian is being appointed. This might be the same person you chose as an agent or it might be someone else.

My Name _____ **DOB**_____ **Date** _____

Part 2 Others Who Are or May Become Involved in My Care

1. My Doctor or other Health care Clinician:

Name _____ Address _____
Phone_____

(or) Name _____ Address _____
Phone _____

2. Other people who MAY be consulted about medical decisions on my behalf:

_____

_____

Those who should NOT be consulted:

_____

3. The following adults and minors will be entitled to information about my condition. _____

_____

4. The person(s) named below shall NOT be entitled to bring court action on my behalf concerning matters covered by this Advance Directive.
Name:_____ Address_____

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5. If I need a **medical guardian** in the future, I ask the court to consider appointing the following person:

____ My health care agent

____ The following person:

Name_____ Address_____

Phone_____

Alternate potential guardians may be listed as well.

Instructions for Part 3 – Statement of Values and Goals

Part 3 allows you to state in your own words what is most important to you as you think about medical care you may receive in the future. This will guide your agent and your health care providers and will let them know why you think particular choices are important based upon your own values and beliefs.

You may wish to use the Worksheet 1 *Values Questionnaire* that is in the VT Ethics Network booklet "Taking Steps" for help in framing and sharing your response, if you choose to fill out this part.

You may also wish to use Worksheet 2 *Medical Situations and Treatment*. The second worksheet helps you consider how you might respond to changing circumstances and the changing chances that medical treatment may be successful.

My Name_____ **DOB**_____ **Date**_____

Part 3 - Statement of Values and Goals

Use the space below to state in your own words what is most important to you.

_____
_____
_____
_____
_____
_____
_____
_____

.... And general advice about how to approach medical choices depending upon your current or future state of health or the chances of success of various treatments.

_____
_____
_____
_____
_____
_____

Instructions for Part 4 - End of Life Wishes.

Part 4 contains statements that you can use to express either a desire for continued treatment or a desire to limit treatment as death approaches or when you are unconscious and unlikely to regain consciousness.

Part 4 allows you to include other things that may be important to you, such as the type of care you would want and where you hope to receive that care if you are very ill or near the end of your life.

There may be other issues about health care when death is not expected or probable. These treatment issues and choices you can address in Parts 5 and 6 if you wish.

There may be questions about your survival that even doctors cannot predict accurately in your case. It is important to repeat that Part 4 is for those situations where you are <u>not</u> likely to survive or to continue living without life-sustaining treatment on a long-term basis.

My Name _____ DOB_____ Date _____

Part 4 End of Life - Treatment Wishes

If the time comes when I am close to death or am unconscious and unlikely to become conscious again (choose all that apply):

1. _____ I **do** want all possible treatments to extend my life. **Or**

2. _____ I **do not** want my life extended by any of the following means:

    ____ breathing machines (ventilator or respirator)

    ____ tube feeding (feeding and hydration by medical means)

    ____ antibiotics

    ____ other medications whose purpose is to extend my life

    ____ any other means

    _____Other (specify) _____

3. _____ I want my **agent to decide** what treatments I receive, *including tube feeding.*

4. _____ I want care that preserves my dignity and that provides **comfort and relief** from symptoms that are bothering me.

5. _____ I want **pain medication** to be administered to me even though this may have the *unintended effect* of hastening my death.

6. _____ I want **hospice** care when it is appropriate in any setting.

7 _____ I would prefer to **die at home** if this is possible.

8. Other wishes and instructions: (state below or use additional pages):

_____
_____
_____
_____
_____
_____

Instructions for Part 5 - Other Treatment Wishes.

Part 5 addresses situations which may be temporary, long-term or which may be part of a health crisis that might become life ending for you if no treatment was given or if it was unsuccessful.

You may want to state your wishes regarding a **"Do Not Attempt Resuscitation" Order (DNR Order)** if your heart were to stop (statement #1). Such an order must be written and signed by your doctor. Either the completed written order, or a special bracelet or other identification of that order, needs to be available for any emergency first responders who are called to the scene when your heart stops. It is up to you or your agent to make sure that these additional steps are taken, including having your doctor complete and sign the order and give you either a copy of the order or some other identification.

You may be in a situation in which there is a chance for recovery but, without treatment, you might die. Statement #2 is about allowing a **"trial of treatment"** in situations like these. This means you want to start treatments that will sustain your life, such as breathing machines or tube feeding, to see if you will recover. If these life sustaining treatments are not successful after a period of time, you give your agent and other care providers permission to stop or withdraw them.

Other statements in this Part concern your wishes about hospitalization and treatment as well as participation in medical student education, or clinical or drug trials as part of your treatment.

There is also a section about mental health treatment and your preferences concerning types of involuntary treatment.

Section 9 of this Part concerns specific directions for prescribing and conducting electro-convulsive therapy (ECT) sometimes called "electro-shock" treatment.

If certain sections of Part 5 do not concern you or apply to you, do not feel you have to address them. If you have an agent, that person will likely know what your wishes and concerns are about most treatments you will likely be offered.

Name _____ DOB _____ Date _____

Part 5 - Other Treatment Wishes

1. _____ **I wish to have a Do Not Resuscitate (DNR) Order** at the appropriate time, given my wishes and values as stated in this Advance Directive.

2. _____ If I am in a critical health crisis that may not be life-ending and **more time is needed** to determine if I can get better, I want my doctor to start treatment. If, after a reasonable period of time, it becomes clear that I will not get better, I want all life extending treatment stopped. This includes the use of breathing machines or tube feeding.

3. If I am conscious but become **unable to think or act for myself** and will likely not improve, I do not want the following life-extending treatment:
   - ____ breathing machines (ventilators or respirators)
   - ____ feeding tubes (feeding and hydration by medical means)
   - ____ antibiotics
   - ____ other medications whose purpose is to extend life
   - ____ any other treatment to extend my life
   - ____ Other Please specify _____

4. _____ If the likely **costs, risks and burdens** of treatment are more than I wish to endure, I do not want life-extending treatment. The costs, risks and burdens that concern me the most are:

   _____

5. _____ If it is determined that I am **pregnant** at the time this Advance Directive becomes effective, I want life sustaining treatment.

6. **Hospitalization - If I need care in a hospital or treatment facility, the following facilities are listed in order of preference:**
   Hospital/Facility_____Address_____Tel.#_____
   Hospital/Facilty_____Address _____ Tel. #_____
   Reason for preference _____
   ***Avoid* use of the following facilities:**
   Hospital/Facility _____ Reason _____
   Hospital/Facility _____ Reason _____

7. **I prefer the following medications or treatments:** Use more space or additional sheets for this section, if needed.

   _____
   ***Avoid* use of the following medications or treatments:**
   List medications/treatments: Why to avoid
   _____
   _____

8. Consent for Student Education, Treatment Studies or Drug Trials

____ I **do/ do not** (circle one) wish to participate in student medical education.
_____ I **do/ do not** (circle one) wish to participate in treatment studies or drug trials.

____ I authorize **my agent to consent** to any of the above.

9. Mental Health Treatment

A. Emergency Involuntary Treatment. If it is determined that an emergency involuntary treatment must be provided for me, I prefer these interventions in the following order: (List by number as many as you choose. For example, 1 = first choice; 2 = second choice, etc. You may also note the type of medication and maximum dosage.)

____ Medication in pill form
____ Liquid medication
___ Medication by injection
____ Physical restraints
___ Seclusion
___ Seclusion and physical restraints combined
___ Other (please specify) _____

Reason for preferences above: _____
_____

B. Electro-convulsive Therapy (ECT) or "Electro-Shock Treatment"

If my doctor thinks that I should receive ECT and I am not legally capable of consenting to or refusing ECT, my preference is indicated below:

____ I **do NOT** consent to the administration of ECT.
____ I **consent/ do not consent (circle one)** to unilateral ECT
____ I **consent/ do not consent (circle one)** to bifrontal ECT
____ I **consent/ do not consent (circle one)** to bilateral ECT

____ I **consent** (or authorize my agent to consent) to ECT as follows:
___ I agree to the # of treatments the attending Psychiatrist considers appropriate.
___ I agree to the # of treatments Dr. _____considers appropriate.
____I agree to the # of treatments my agent considers appropriate.
___ I agree to no more than the following number of treatments___.

Other instructions regarding the administration of ECT:

Instructions for Part 6 - Waiver of Right to Request or Object to Treatment

Part 6 is a special part that may be used by people who want their future responses to offered health treatment disregarded or ignored.

There may be situations in which you might be objecting to or requesting treatment but would then want your objections or requests *to be disregarded.* If you have had treatment in the past that scares you or is uncomfortable or painful you may be likely to say "no" when it is offered in a future health crisis. Still, you may know that this is the only way for you to come through a bad time or even survive. You understand that it is necessary and you would want it again if you had to have it. This part will help you let your agent, your family and others know what you *really* want for yourself. You may fill out Part 6 of your Advance Directive to address specific treatment situations. You must have an agent to fill out this Part.

Because this is signing away a basic right that all patients are supposed to have (to refuse to give consent to treatment), you will need to give this much careful thought. You will also have to have additional signatures and assurances at the time you fill out this Part of your Advance Directive.

If you think this Part 6 could apply to you and be helpful in your case, you need to be sure that everyone involved in your care understands that you are making this choice of your own free will and that you understand the ramifications of waiving your right either to consent or to object to treatment.

Unlike other Parts of your Advance Directive, you can revoke Part 6 *only when you have capacity to make medical decisions* as determined by your doctor and another clinician.

My Name _____ DOB _____ Date _____

Part 6 - Waiver of Right to Request or Object to Treatment in the Future

For your agent to be able to make healthcare decisions over your objection, you must:

- Specify what treatments you are allowing your agent to consent to or to refuse over your objection;
- State that you either do or do not desire the specified treatment even over your objection at the time and, further, specify your wishes related to voluntary and involuntary treatment and release from that treatment or facility;
- Acknowledge in writing that you are knowingly and voluntarily waiving the right to refuse or receive specified treatment at a time of incapacity;
- Have your agent agree in writing to accept the responsibility to act over your objection;
- Have your clinician affirm in writing that you appeared to understand the benefits, risks, and alternatives to the proposed health care being authorized or rejected by you in this provision; and
- Have an ombudsman, recognized member of the clergy, attorney licensed to practice in Vermont, or a probate court designee affirm in writing that he or she has explained the nature and effect of this provision to you and that you appeared to understand this explanation and be free from duress or undue influence of others.

I hereby give my agent the authority to consent to or refuse the following treatment(s) *over my objection* if I am determined by two clinicians to lack capacity to make healthcare decisions at the time such treatment is considered:

1. **I do want** the following treatment to be provided, even over my objection, at the time the treatment is offered:

   _____

   _____

   I do not want the following treatment, even over my request for that treatment, at the time the treatment is offered:

   _____

2. I give permission for my agent to agree to have me admitted to a designated hospital or treatment facility even over my objection.
   ____Yes _____No
3. I give my agent permission to agree that my release from a voluntary admission for mental health treatment may be delayed even over my objection for up to four days so that a decision can be made regarding whether I meet criteria to be involuntarily commited.
   _____Yes _____No
4. I hereby affirm that I am knowingly and voluntarily waiving the right to refuse or request specified treatment at a time of incapacity, and that I

understand that my doctor and one other clinician will determine whether or not I have capacity to make health care decisions at that time. I know that I can *revoke* this part of my Advance Directive only when I have the capacity to do so, as determined by my doctor and at least one other clinician.

Signed _____, Principal Date _____

Acknowledgement of Agent, Clinician and Persons who explain Part 6:

Acknowledgement by Agent - I hereby accept the responsibility of consenting to or refusing the treatments specified above, even if to do so would be against the principal's expressed wishes at the time treatment is considered.

Signed: _____(Agent)and_____(Alternate)
Please print names:)_____ _____
Date_____ Date_____

Acknowledgement of principal's clinician - I affirm that the principal appears to understand the benefits, risks, and alternatives to the health care specified above that is being consented to or refused by the principal.

Signed: _____Title____ Facility ____
Date_____Please print name: _____

Acknowledgement by persons who explain Part 6 - I, as the designated person to explain Part 6, affirm that I am an ombudsman, recognized member of the clergy, an attorney licensed to practice in Vermont, or a probate court designee and that I have:

- Explained the nature and effect of this Waiver of the Right to Request or Object to Treatment to the principal, and
- The principal appears both to understand the nature and effect of this provision and to be free from duress or undue influence.

- If the principal is in a hospital at the time of signing, that I am not affiliated with that hospital, and
- I am not related to the principal, a reciprocal beneficiary, or an "interested person" defined as the principal's clergy or persons who have exhibited special care and concern for the principal.

Signed: _____Position_____ Date _____

Instructions for Part 7 - Organ and Tissue Donation

Part 7 of your Advance Directive allows you to state your wishes about organ and tissue donation.

In some European countries organ donation is mandatory unless the patient has objected in advance. In our country permission for organ donation is not assumed and often the family or next of kin are approached at the time of an accidental death or other circumstance. If there are any objections from the family, those reservations and refusals are honored. Consequently, many people who may have wanted their organs and tissues to benefit others do not get to have their own wishes honored. That is one reason why there is such a shortage of usable organs and tissues for transplant in our country and why many people die waiting for needed transplants.

Although you may elect to have an agent or your family decide on organ and tissue donation, your organs are more likely to be of use for others if you make the decision yourself.

You should also note your wishes on your license and include the sticker that you wish to be an organ donor. You do not have to have an Advance Directive form filled out to show evidence of your wishes to be an organ donor, particularly if your license identification includes your wishes about organ donation.

If you wish to donate your body for research to a medical school you will need to contact that institution to make separate arrangements and fill out forms supplied by that institution.

My Name _____ **DOB** _____ **Date** _____

Part 7 - ORGAN and TISSUE DONATION

I want my agent (if I have appointed one) and all who care about me to follow my wishes about organ donation if that is an option at the time of my death. (Initial below all that apply.)

_____ **I wish to donate the following organs and tissues:**

____ any needed organs or tissues

____ major organs (heart, lungs, kidneys, etc.)

____ tissues such as skin and bones

____ eye tissue such as corneas

_____ I desire to donate my body to research or educational programs. (Note: you will have to make your own arrangements through a Medical School or other program.)

_____ **I do <u>not</u> wish to be an organ donor.**

Instructions for Part 8 - Disposition of My Body after Death

Part 8 allows you to give directions about funeral arrangements or related wishes about the final disposition of your body after you die.

You can use the section to appoint an agent for making these arrangements, or you may say that family members should decide this together. You can give directions to whomever is in charge.

You can list important information about any pre-need arrangements you have made with a funeral home, cremation service or the location of family burial plots.

You may indicate your permission to have an autopsy done on your body after your death. An autopsy is generally not suggested or needed when the cause of death is clear. If an autopsy is suggested, it could be helpful to your agent or family to know your wishes about having an autopsy performed. Autopsies may be *required* in cases where abuse, neglect, suicide or foul play is suspected.

My Name _____ **DOB**_____ **Date** _____

Part 8 - My Wishes for Disposition of my Body after my Death

1. My Directions for Burial or Disposition of My Remains after Death.

_____ I want a funeral followed by burial in a casket at the following location, if possible (please tell us where the burial plot is located and whether it has been pre-purchased): _____

_____I want to be cremated and want my ashes buried or distributed as follows:

_____

_____ I want to have arrangements made at the direction of my agent or family.

Other instructions:_____

(For example, you may include contact information for Medical School programs if you have made arrangements to donate your body for research or education.)

2. The person I want to serve as my agent for disposition of my body:

____ I want my **health care agent** to decide arrangements after my death.
_____If he or she is not available, I want my alternate agent to decide.
_____I appoint the following person to decide about and arrange for the disposition of my body after my death:

Name _____ Address_____
Telephone _____ Cellphone_____ Email_____

(or)
_____ I want my family to decide.

3. **If an autopsy is suggested following my death:**

_____ I support having an autopsy performed.
_____ I would like my agent or family to decide whether to have it done.

4. **I have already made funeral or cremation arrangements with:**

Name_____Tel._____

Address_____

Instructions for Part 9 - Signature and Witnesses

Congratulations! You have done much good work in sharing your wishes through the completion of your Advance Directive.

Be sure that your wishes as stated in the Parts you have chosen to fill out make sense when read together as a whole. If there is a question of conflicting wishes, be sure that you have indicated your priorities.

When you sign your Advance Directive, you must have **two adult witnesses.** Neither witness can be your spouse, agent, brother, sister, child, grandchild or reciprocal beneficiary. A change in Vermont law has made it a little easier to have witnesses available to assist you. For example, your health care or residential care provider and their staff now *can* be witnesses of Advance Directives.

If you are in a hospital, nursing home or residential care facility when you complete your Advance Directive, you will need a third person's signature to certify that he or she has explained the Advance Directive to you and that you understand the impact and effect of what you are doing. In a health care facility, this third person may be a hospital designee, a long-term care ombudsman, an attorney licensed to practice in Vermont, a clergyperson or a Probate Court designee. (Note: If you decide to include **Part 6** when you are in a health care facility, you must be sure that the third person who signs your document in that Part is not affiliated with or employed by the health care facility.)

Distribution of Copies of this Document

It is a good idea to make sure that your agent, your family, your personal physician and your nearest hospital or medical facility all have copies of this Advance Directive. List the people to whom you give copies at the end of Part 9 of the Advance Directive form. This will be make it easy for you to remember to tell all of these people if you decide to cancel, revoke or change this document in the future.

By mid - 2006 you will also have the option to have your advance directive scanned into a computerized databank called an **Advance Directive Registry** where you, your agent, your health care facility and others you designate, can get copies of your advance directive (including special personal handwritten instructions) immediately.

My Name _____ DOB ____ Date_____

Part 9 - Signed Declaration of Wishes

I declare that this document reflects my desires regarding my future health care, (organ and tissue donation and disposition of my body after death,) and that I am signing this Advance Directive of my own free will.

Signed _____ Date_____

(Optional) I affirm that I have given or will give copies of my Advance Directive to my Agent(s) and Alternate Agent(s) and that they have agreed to serve in that role if called upon to do so.
Signed _____ Date: _____

(Optional) I affirm that I have given or will give a copy of my Advance Directive to my Doctor or Clinician.
Signed _____ Date: _____

Acknowledgement of Witnesses

I affirm that the Principal appears to understand the nature of an Advance Directive and to be free from duress or undue influence.

Signed _____ Date _____
Print name: _____

Signed _____ Date _____
Print name:_____

Acknowledgement by the hospital explainer or long-term-care Ombudsman or clergyperson, attorney, or probate court designee if the principal is a current patient or resident in a *hospital, or other health care facility.*

I affirm that:

- the maker of this Advance Directive is a current patient or resident in a hospital, nursing home or residential care facility,
- I am an ombudsman, recognized member of the clergy, an attorney licensed to practice in Vermont, or a probate court or hospital designee, and
- I have explained the nature and effect of the Advance Directive to the Principal.

Name_____Address _____

Title/position_____ Date _____ Tel. _____

Important!

Please list below the people and locations that will have a copy of this document:

_____**Vermont Advance Directive Registry** (anticipated available by mid- 2006)

____ **Health care agent(s)**

____ **Alternate health care agent**

_____ **Family members:** (List by name all who have copies)

Name_____ Address_____

_____

_____

_____

_____

_____

_____ **MD** (Name)_____Address_____

_____ **Hospital** (s) (Names)_____

_____ **Other individuals** or locations:

_____

_____

_____

_____